

blisters on the skin, eyes, throat, and internal organs. Children with EB are often called “butterfly children” because their skin so fragile. As with most rare diseases, EB can vary in progression and severity among its various types and subtypes.

The most severe form of EB, recessive dystrophic EB, puts children at especially high risk for infection. Typically, even a mild localized trauma can cause skin to fall off, leading to open sores that do not heal, which cause indescribable pain and agony. In addition to the risk of infection, other conditions associated with EB include cancer, heart failure, malnutrition, and foot and hand deformities.

I have heard the heartbreaking stories of children with this form, such as Rafi Kopelan and Jackson Silver of New York City and Mikey Fullmer of Irvine, California. Imagine being eight years old, unable to play soccer or swim, covered in bandages, enduring regular painful vinegar and bleach baths, and fighting through the discomfort to eat and breathe. This has been a reality for kids like Rafi, Jackson, and Mikey.

New York City is home to two of the three leading patient advocacy and research organizations representing the EB community—debra of America and the EB Research Partnership. I would like to recognize the tremendous impact both organizations, as well as the Los Angeles, California based EB Medical Research Foundation, are having on the community. Due to their efforts, several drug manufacturers are currently in the research and development phase for various treatments for EB—from topical creams to protein replacement therapies.

The Rare Pediatric Disease Priority Review Voucher Program has been instrumental in creating an incentive for these companies to finally allocate resources to investigating potential solutions for children with EB beyond pain management and wound care. But more progress is needed. Further research is necessary, for example, to develop interventions against a particularly virulent form of squamous cell carcinoma in EB patients, which has a mortality rate approaching 90 percent.

Congress has long supported EB research funding through the National Institutes of Health, which has helped lay the foundation for these existing development programs. Reauthorizing the Rare Pediatric Disease Priority Review Voucher Program, however, is a critical way of providing the necessary incentives to ensure children like Rafi, Jackson, and Mikey will soon benefit from this important research in the form of FDA-approved therapies.

We must not let this deadline slip and this important program expire, and I hope all my colleagues recognize the urgency of this issue.

#### PERSONAL EXPLANATION

### HON. JAMES A. HIMES

OF CONNECTICUT

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. HIMES. Mr. Speaker, on July 13, 2016, I was unable to be present to cast my vote on amendments Number 76 and Number 78 to H.R. 5538, the Department of the Interior, Environment, and Related Agencies Appropriations Act, 2017. I wish to reflect that had I

been present for roll calls No. 453 and 454, I would have voted “nay.”

#### RECOGNIZING POTTSTOWN SUPERINTENDENT DR. JEFFREY R. SPARAGANA

### HON. RYAN A. COSTELLO

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. COSTELLO of Pennsylvania. Mr. Speaker, I rise today to recognize Pottstown School District Superintendent, Dr. Jeffrey R. Sparagana, as he prepares to retire after a career in education spanning more than four decades.

For the past 23 years, Dr. Sparagana has held a variety of teaching, administrative, and coaching positions in the Pottstown School District. He was appointed superintendent in December 2012, demonstrating outstanding leadership during what his colleagues described as “the most tumultuous period of change” in the District’s 177-year history. It was a period that saw the District revise attendance boundaries, close one elementary school and renovate four others, and realign the Middle School to include fifth grade. Innovation, a commitment to academic excellence and accountability and an incredible ability to collaborate with teachers, parents and the community were hallmarks of Dr. Sparagana’s tenure. Those traits undoubtedly contributed to Pottstown earning national accolades for its PEAK program, which ensures students start kindergarten properly prepared for a lifetime of learning. Pottstown students also benefit from a healthy living program, one of just 20 comprehensive high school programs in the Commonwealth of Pennsylvania, virtual and alternative learning academies for customized instruction and an active Foundation for Pottstown Education, which provides supplemental funding for unique educational opportunities.

Despite the tremendous demands as the top educator in a district with 3,200 students, Dr. Sparagana always was an engaged citizen and made countless positive contributions to the greater Pottstown community. He is a past president of the Pottstown Area Industrial Development organization, helped facilitate quarterly joint meetings with the District and Pottstown Borough Council and fostered partnerships with Montgomery County Community College and The Hill School, resulting in Pottstown CARES days during which more than 600 volunteers pitch in on an array of projects in the community.

Mr. Speaker, I ask that my colleagues join me in expressing gratitude for Dr. Jeffrey R. Sparagana’s more than 40 years of outstanding service as an educator and genuine passion for ensuring that each student in the Pottstown School District has the opportunity to learn and develop into a responsible, engaged citizen and offering best wishes for a long, healthful retirement.

#### S CORPORATION MODERNIZATION ACT

### HON. DAVID G. REICHERT

OF WASHINGTON

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. REICHERT. Mr. Speaker, yesterday, Representative RON KIND and I reintroduced the S Corporation Modernization Act to reform and repeal unnecessary rules and limitations on S Corporations. This bill supports growth in communities across the country and builds upon last year’s success. With broad bipartisan support in December, Congress passed the Protecting Americans from Tax Hikes (PATH) Act that provided permanent built-in gains tax relief for S Corporations. The legislative history of this provision makes clear that Congress intended this permanent relief for built-in gains to also apply to Real Estate Investment Trusts (REITs) and mutual funds.

#### HONORING MARALIN NISKA

### HON. JANICE HAHN

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Ms. HAHN. Mr. Speaker, I rise today to honor the memory of Maralin Niska who passed away at home in Santa Fe, New Mexico on July 9, 2016. Maralin sang leading roles with both the Metropolitan Opera and the New York City Opera and was widely known as one of the greatest talents of her generation. She was not only an acclaimed soprano, she was a devoted teacher who loved sharing her passion with admirers and her community.

Born in San Pedro, California, on November 16, 1926, Maralin Niska showed early promise as a musical student. In her youth, she performed as a young soloist in the First Presbyterian Church of San Pedro as well as with the Los Angeles Philharmonic. Despite the advice of teachers and friends, she refused to go to Europe to study and build a career. She told the New York Times, “I’ve never even been to Europe, and I don’t have any desire to go . . . I’m still one of the few holdouts who are truly American in training, experience, everything.” She never wavered in her love for her community and country. Ms. Niska completed her degree at the University of California, Los Angeles (UCLA), in English literature and continued to study voice at the University of Southern California (USC) and UCLA. All the while, she continued to sing as a resident soloist at several community churches.

Ms. Niska had a rewarding career in education and was a Torrance elementary school teacher for seven years, while continuing to perform for local opera companies and the community. She loved teaching, and appreciated all students at whatever level they could achieve. In 1968, Ms. Niska sang the title role in *Madama Butterfly* for the opening of the new house at the Santa Fe Opera. After retiring in Santa Fe, Ms. Niska continued her passion for teaching and maintained a private vocal studio. There, she taught Master Classes to aspiring students who shared her love for music. The Arizona Daily Star even wrote that Ms. Niska left “most of the traditional diva

arrogance back in the dressing room . . . She offered no-nonsense criticism to her students but tried not to trample their ego.”

Niska’s dramatic talents earned her a reputation as a singing-actress. Ms. Niska appeared regularly with some of the great conductors of her time, including Pierre Boulez, Eric Leinsdorf, and Andre Kostelanetz. She received national recognition when she debuted at the opening of the Metropolitan Opera National Company in 1965. Followed by her debut, she was engaged by the New York City Opera and commanded dozens of roles. In all she sang 29 leading roles with the company—the most of any singer in its history.

Ms. Niska gave her last professional performance in 1996, in Santa Fe, performing arias of Mozart with the Música de Cámara Orchestra conducted by her husband, the famous violinist and renowned conductor, William Mullen. The couple established Music One, a predecessor to Performance Santa Fe, a performing arts center. Maralin Niska was loved by all and will be sorely missed by her husband, students, the greater communities of Los Angeles and Santa Fe, and by opera lovers all over the world.

#### RARE PEDIATRIC PRIORITY REVIEW VOUCHER PROGRAM

#### HON. G.K. BUTTERFIELD

OF NORTH CAROLINA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. BUTTERFIELD. Mr. Speaker, I rise today to express my hope that the House of Representatives will reauthorize the Rare Pediatric Priority Review Voucher (PRV) Program before its expiration deadline of September 30, 2016. I urge my colleagues to consider and pass H.R. 1537, the Advancing Hope Act of 2015 which I introduced with Representative MICHAEL McCaul (TX-10) and would permanently reauthorize the Rare Pediatric PRV Program.

The Creating Hope Act, which was signed into law by President Obama in 2012 as part of the PDUFA reauthorization, expanded the cost-neutral Food and Drug Administration (FDA) priority review voucher (PRV) program, allowing pharmaceutical companies to expedite FDA review of more profitable drugs in return for developing treatments for rare diseases. The Creating Hope Act was reauthorized for Fiscal Year 2016 through the budget agreement passed at the end of last year, but is scheduled to expire soon. The Butterfield-McCaul bill would reauthorize the program, clear the way for more treatments to reach the people that need them most, and clarify the scope of the program to include diseases like Sickle Cell Anemia.

There are many pediatric disease spaces where treatments are woefully inadequate or nonexistent, and the Advancing Hope Act of 2015 would help encourage the private sector to help find solutions. An example of a condition that could benefit from the reauthorization of the Rare Pediatric PRV Program is Alternating Hemiplegia of Childhood, known as AHC, which leads to life-threatening temporary paralysis in approximately three hundred children nationwide. Duke Children’s Hospital and Health Center, located in North Carolina’s First Congressional District, assists North Caro-

linian children Matthew Wuchich, Madison Pino, and Marley Pino, manage their conditions. However, they often have to travel long distances for care or be pulled out of school, and there is no cure in sight.

Mr. Speaker, I urge my colleagues to reauthorize the Rare Pediatric PRV Program before the program expires in September. Congress must do all it can to encourage the development of cures for children like Matthew, Madison, and Marley.

#### PERSONAL EXPLANATION

#### HON. STEVAN PEARCE

OF NEW MEXICO

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. PEARCE. Mr. Speaker, on Roll Call Number 454, on the Gosar amendment on H.R. 5538, I am not recorded because I was representing constituents on business outside of Washington, D.C. Had I been present, I would have voted Aye.

#### IN RECOGNITION OF THE WEST- PORT RIVER WATERSHED ALLI- ANCE

#### HON. WILLIAM R. KEATING

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. KEATING. Mr. Speaker, I rise today in recognition of the Westport River Watershed Alliance on the occasion of its 40th anniversary.

The Watershed Alliance, originally created to protest a septic-composting lagoon project on the Upper East Branch of the Westport River, was established by a small group of 14 concerned Westport residents. What started as a single protest in 1976 has grown to a membership of over 1,500 families and 4,800 volunteers that work on numerous conservation projects from running the longest water quality monitoring program in Massachusetts to planting over 20,000 beach grass seedlings in the past decade to stabilize eroded areas of the Town Beach dune system in the Commonwealth.

The Watershed Alliance has successfully given voice to the natural resource concerns of the Westport River. It has become a leader in environmental preservation efforts in the region and represents the best of the Westport community. The Watershed Alliance has, over the years, worked with state legislators to remove granite blocks out from underneath a bridge that restricted flow to the Upper East Branch part of the river, it has hosted over 28 River Day festivals, has planted 6 rain gardens at the Westport Middle School which were used to capture and treat over 60% of the storm water that flowed previously unchecked into the water, and it is working with the Town of Westport and MA Estuaries Project to come up with alternatives to expensive sewer treatments to help solve the nitrogen pollution problem in an efficient and affordable manner.

Mr. Speaker, I rise to congratulate the Westport River Watershed Alliance’s four decade commitment to protecting the Westport River.

I ask that my colleagues join me in honoring the service and commitment of the members of the Westport River Watershed Alliance.

#### CONSCIENCE PROTECTION ACT OF 2016

SPEECH OF

#### HON. BARBARA LEE

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, July 13, 2016*

Ms. LEE. Mr. Speaker, I rise today in strong opposition to S. 304, the so-called “Conscience Protection Act.”

This bill would open the door for employers and companies to discriminate against women based on their reproductive health choices. And it puts the personal beliefs of any employer or healthcare provider above the health and safety of women.

Once again, Mr. Speaker, my colleagues on the other side of the aisle are using the pretext of religious liberty to violate the fundamental human rights of women.

This bill is another in a long line of Republican attempts to limit women’s access to safe, legal abortion—like the Weldon and Hyde amendments.

Let me be clear: no employer or politician has the right to interfere with a woman’s personal healthcare choices. These decisions belong to women—not politicians or bosses.

Mr. Speaker, this bill is dangerous.

Instead of addressing the serious issues facing American families—like combatting Zika, addressing gun violence, or creating jobs—my colleagues have chosen to put partisan politics over healthcare access.

This is just shameful.

I urge my colleagues to vote no on this outrageous attack on women’s health.

#### IN RECOGNITION OF LIEUTENANT COLONEL DENNIS SCHMIDT

#### HON. BARBARA COMSTOCK

OF VIRGINIA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mrs. COMSTOCK. Mr. Speaker, I rise to acknowledge my constituent Dennis Schmidt from Fairfax Station, Virginia, a former Lieutenant Colonel in the United States Army and lifelong dedicated public servant. Mr. Schmidt devoted twenty-one years of his life to the United States Army, including assignments and deployments during the Vietnam War. After he completed his military service, his dedication to public service did not stop.

Between 1989 and 1993, Mr. Schmidt worked for the Army Research Laboratory in the Army Materiel Command, during which he helped develop technology over multiple fields such as weapons systems, medical equipment, and protection tools. This research has helped save American lives, and gives our soldiers an edge in the performance of their duties to our country. From 1994 to 1998, Mr. Schmidt refocused his talents as acting Science and Technology Advisor to the Director for Force Development, where he evaluated and managed the Army’s annual research programs budget. Through such